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Beyond autism and technology: Lessons from neurodiverse populations

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Abstract

Purpose – This short paper reports on the sixth seminar in a 7-seminar series entitled, “Innovative Technologies for Autism: Critical Reflections on Digital Bubbles”, funded by the UK Economic and Social Research Council (ESRC). The aim of this particular seminar was to reflect upon the implications from neurodiverse communities for the development of technology for autism.

Design/methodology/approach – Presentations from key researchers and parental perspectives are reviewed, highlighting contemporary issues in neurodiverse populations that have important implications for autism.

Findings – Whilst there are many conditions associated with autism, most commonly intellectual disability (learning difficulties), this is not reflected in research. In addition, for child-based research, researchers are at least a generation older than participants and have had different digital-childhoods. Involving neurodiverse populations within participatory design sessions can address both of these issues. Understanding the context of the issues that the participatory design sessions address is crucial for developing participatory design principles that extend from one condition to another. This includes understanding when findings based upon verbal populations can be extended to nonverbal populations.

Originality/value – This paper offers up-to-date insights into how design principles from one condition extend to different conditions. Universal interaction and neurodiversity HCI are considered. This is important within neurodiverse populations, especially given the high rates of additional conditions that are associated with autism. Whilst the majority of autism research has involved verbal populations, the benefits of technology can extend to non-verbal populations.

Keywords – Innovative technologies, autism, neurodiversity, inclusion, design principles.
Paper type – Project report

The ‘Digital Bubbles’ seminar series: The diversity bubble

People with a diagnosis of autism often have other conditions (Simonoff et al., 2008).

Intellectual Disability (or Learning Difficulties) is the most common, with 56%-73% of children with a diagnosis of autism having an IQ of less than 70 (Baird et al., 2006). The range in estimates in the overlap between autism and learning difficulties is due in part to varying definitions of the conditions (see O’Brien and Pearson, 2004, for a review).

This high prevalence of associated learning difficulties in autism, however, is not generally reflected in autism research (see Pellicano et al., 2013). Understanding the diversity of autistic people not only enables the field to reflect the population better, but according to the latest seminar in the ‘Digital Bubbles’ series [digitalbubbles.org.uk] on neurodiversity, can also bring advantages in understanding that can inform technology design. For example, it is advantageous to the area to understand whether the benefits of participatory design involving autistic children (Brosnan et al., 2016) extend to children with intellectual disability or children who have other special education needs or disabilities (SEND). A specific example is to better understand the extent to which the benefits of social media for autistic young people (Parsons et al., 2015) extend to young people with cerebral palsy. The consideration of overlapping or co-occurring conditions is consistent with the work of Gillberg (2010) who has proposed the ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) framework under which the symptoms for neurodevelopmental disorders such as autism and intellectual disability (as well as ADHD, language impairment etc.) are considered concurrently, rather than involving separate diagnostic procedures for each disorder.

Technology for Autism and Intellectual Disability (ID): Parental perspectives

Despite the relative paucity of research with autistic children who also have an intellectual disability, valuable insights can be gained from the anecdotal accounts of parents. A mother of a child with a diagnosis of autism with intellectual disability provided the following account of her son's use of technology at the seminar:

I almost always take the iPad when we go to restaurants and cafes as it entertains him whilst waiting for food. This can focus 'G' and I don't feel there is a stigma attached to having children use technology in these 'family time' situations and, for us, it's the difference between going or not going out! I've noticed that he loves watching videos of other children play (children at a soft play barn, children in the park, playing with the dolls and cars etc.) and clearly, as a child, still has the desire to play but just doesn't know how and doesn't come natural to him.

This anecdotal account of technology use by a child with autism and intellectual disability highlights two enabling factors. Firstly, the wider family is enabled to go out for family time, and secondly, the child himself is enabled to vicariously experience typical childhood play activities that he does not have the practical skills to actively negotiate otherwise.

Samantha Holt, who has a 24-year-old daughter, Rebecca, with autism and severe learning difficulties, was the first speaker. The experience of parenting a child with autism led Samantha to become a psychologist and complete a PhD (University of Sussex) investigating collaboration in children with autism using shareable technology

(Holt & Yuill, 2014, 2016). Samantha provided the following account from a parent's perspective:

Rebecca is totally dependent on family and carers to keep her safe and to meet her daily needs; to wash and dress her, make meals she will eat and crucially provide the predictable routine she desires. Although Rebecca enjoys producing many vocal sounds and does use sign language, she cannot speak.

Technology for Rebecca means media players including a VCR, portable DVD players, two iPads and a CD player. Everywhere she goes she insists on taking a selection of videotapes and discs with her. At the breakfast table, she will not sit down or eat until she has her DVD player and iPad playing her favourite movies simultaneously. In this content mood she will reach for her Dad to sit beside her and sing to her while she sways in time.

Rebecca finds leaving the house difficult and we have to give her plenty of time to choose discs and videotapes to take with her. She watches DVDs on the journey to her day centre and will leave the player in the car. However, when we collect her she immediately searches for it and if it is out of charge will gesture for it to be plugged into the car's power socket. At home she likes to hold a player close to her ear when she is on her swing or spinning or entertains herself with her favourite movies playing on the VCR, DVD and iPad simultaneously. However, for short periods during the evening she will choose to sit close to someone smiling and cuddling them to share the movie she is enjoying.

Although Rebecca's love (or perhaps obsession) with media players can be beneficial, it can also be extremely challenging. For example, portable DVD players frequently break,

and Rebecca only likes one brand, and now DVD players are obsolete we have to trawl the internet to find them. We have given her different brands of player, but she will not use them and we find them in the bin. Obsolete technology is a worry as unless Rebecca's environment is just as she likes it she becomes irritable, anxious and unable to sleep and will even self-harm, whereas once the status quo is returned, she instantly returns to her normal happy self. Media players can be used to comfort and motivate Rebecca, for example access to her VCR was instrumental in toilet training and significantly, 'video' was one of the first signs she used spontaneously. Rebecca finds going to the doctors and dentist incredibly stressful and I have learnt to always go with a fully charged player to distract and comfort her.

Despite Rebecca's severe learning difficulties, her ability to learn about and use technology far exceeds expectations. It took less than half an hour to teach her how to use an iPad independently. She understands technology needs power, and will plug them in when they run out of charge. She also knows dirty discs and players will not work and she will try to clean them or give me a cloth and sign for help. Even so, it is the social interaction that she initiates using her players that I believe is significant.

When Rebecca was growing up I was desperate to help her and unfortunately I tried many interventions with little or no evidence base. At best they were costly, but at worst they were time consuming, and time for a young child with autism is precious. Therefore, it is crucial for researchers to produce interventions with a good evidence base, and to share their findings with practitioners, clinicians and families. I urge professionals to be mindful that each child with autism has only one childhood.

Universal Interactions

JP Hourcade from the University of Iowa gave a talk which developed the argument that there are 'universal interactions', such that technology can be designed to be universally beneficial for all users – although this does present a series of challenges (Hourcade & Bullock-Rest, 2011). Firstly, children have very different digital experiences throughout their childhood as compared to their parents. 'Digital immigrants' are therefore designing interactions for 'digital natives' (after Prensky, 2001a;b). Involving children within participatory design (see Brosnan et al., 2016) may ameliorate this to some degree because their unique perspectives and experiences can be incorporated. However, the implementation of the outputs from participatory design sessions are still likely to be undertaken by digital immigrants to some degree. Secondly, whilst there might be technology design guidelines for single impairments, there are no guidelines for multiple impairments. Given the high levels of associated conditions with autism, outlined above, this is a crucial limitation of current technology design. Thirdly, access does not lead to equality. As with the example email above, iPad technology enabling 'G' to access films of children playing has not enabled him to actively play in the same manner.

Hourcade proposed that designing for universal interactions therefore needs to address the fact that end-users are different from developers; they may be difficult to access; and the end-user population may contain high variability. Four key principles can help to address these issues (Alper, Hourcade & Gilutz, 2012):

- 1) Deep engagement – technology should arise from people's needs, abilities, preferences and contexts;

- 2) Interdisciplinarity – maximize the benefits from integrating between and within disciplines;
- 3) Individuality – one size does not fit all;
- 4) Practicality – beyond access, the technology has to be useable (for example, considering additional issues arising from designing for people in poverty).

Hourcade (2015) has developed the APPS acronym to inform universal interactions – Access, Participation, Personalization, Sustainability. He has a self-published, freely available book which can be downloaded at: www.childcomputerinteraction.org

Diversity for design

Asimina Vasalou from the UCL Knowledge Lab also addressed the context of designing for a wide range of children who have a special educational needs or disability (SEND). She argued that participatory design is a social constructivist, situated research approach where knowledge about users' values, needs or concerns is the outcome of an interaction between context, design and the people involved. This is particularly pertinent to working with children who have a special education need or disability as unnecessary silos can develop around specific groups of children (a 'digital bubble' in the language of our seminar series!), when potential benefits can be shared between research on different disabilities – as long as the research is 'trustworthy'.

According to Vasalou, three criteria characterize the trustworthiness of research: transferability, credibility and authenticity (see also Lewis, 2002). Transferability involves the full articulation of the research context to enable others to assess if and how the research knowledge transfers, so that knowledge is reusable. Key questions concerning credibility and authenticity are: 1) Does what occurred during the

participatory design session match the planned participatory design protocol and the evaluation of what occurred within the participatory design session? and 2) Are multiple voices and realities heard within participatory design methods? Adherence to these criteria can guide the development of participatory design methods and analytic approaches such that they strengthen knowledge exchange and dialogue across different groups of children with SEND.

Diversity for Design (D4D) is a new participatory design framework that provides guidance for technology designers working with neurodiverse children in establishing participatory design methods that capitalize on children's strengths and also support their potential difficulties. The D4D framework explicitly seeks to understand the cultural and individual aspects of learning when considering both the structuring of the design environment as well as the additional supports in the design activities. Vasalou presented a case study in which the theory-informed and the practice-informed structured design environment and additional supports for children with autism could be extended to children with dyslexia (see Benton et al., 2014; see also Benton et al., 2011; 2012). Specifically, understanding the culture of autistic learning, such as a preference for familiar environments, consistent session structure, and a preference for a visual schedule to organise activities may confer benefits for autistic learners. Similarly tailoring to the individual, such as themed material in line with the autistic learners' special interest, may also be beneficial for dyslexic learners. In this way, theory-informed and practice-informed participatory design to maximize the strengths of one group of learners can inform the development of participatory design methods to maximize the strengths of a different group of learners. According to Vasalou, this is consistent with Dalton (2013) who argues that 'Neurodiversity HCI' should seek ways to

harness the neurodiverse population's gifts, which would also yield benefits to the greater world.

Social media and Augmentative & Alternative Communication (AAC)

Amanda Hynan, from Leeds Beckett University, argued that physical disability and complex communication needs can affect social participation opportunities and that being online may help overcome the challenges of face-to-face communication for people who use Augmentative and Alternative Communication (AAC). Literacy and language challenges are barriers for text-based Internet sites, and people who use AAC often use symbol-based vocabularies. AAC devices (including those that are symbol-based) can include social media tools, thereby enabling increased access to online information and opportunities.

Hynan et al. (2014) interviewed 25 young people with cerebral palsy (aged 14-24) who used AAC to investigate self-reported experiences of the accessibility of the Internet and social media. The aim was to explore the perceived role and importance of the Internet and social media for self-determination and self-representation, and to establish how social media is perceived in terms of social ties for people who use AAC. The central phenomenon, reported in Hynan's paper was the desire by this group to use the Internet and social media. The positive consequences of access to the Internet and social media were enhanced self-determination and self-representation. Self-determination related to independent access to information, enhanced privacy, an ability to organise own activities, enhanced employment and voluntary charity work opportunities as well as enhanced capacity to support others. Self-representation related to enriching existing and creating new friendships (including dating

opportunities). AAC that enables access to the Internet and social media was felt to both reduce isolation and enhance resilience (Hynan, 2013; Hynan et al., 2014; 2015).

Key messages

Most people with a diagnosis of autism also have an additional condition. ‘Designing for people with autism’ therefore necessitates considering the design requirements related to other conditions, if the majority of the autism community are to benefit maximally. As there are a range of conditions associated with autism, this presents significant challenges to those seeking to engage with participatory design methods. Because most children with autism have an IQ below 70 (Baird op cit.), considering the impact of intellectual disability/ learning difficulties is essential. The relevance of participatory design methods (and research generally, see Pellicano et al., 2013) for those with autism and learning difficulties needs to be established rather than assumed.

Neurodiversity is broader than just autism and learning difficulties, and valuable lessons can be shared between researchers developing technologies for different developmental conditions. It is therefore incumbent upon researchers to ensure their participatory methods embrace transferability, credibility and authenticity in their application and dissemination.

Universal interactions, Diversity for Design, and Neurodiversity HCI are useful frameworks for extrapolating potential commonalities between participatory design methods from different populations. ‘Deep engagement’ with the end users of technology from an interdisciplinary perspective will ensure appropriate elements from

participatory design protocols can be shared between different conditions, rather than assuming a 'one size fits all' model.

The broader context of the person with autism is also crucial to consider, especially in relation to those who provide support, such as parents. Technology can support the family as well as the autistic individual. Additionally, parents can often determine into which digital interventions to invest time and money for their autistic child and so their involvement in the research agenda remains essential.

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